



Guidance note for parents and professionals when considering a treatment approach in autism

There are now a bewildering number of approaches and treatments available in autism. Parents and professionals are often in a dilemma as to which approach may be best suited to their circumstances. Many approaches may be well packaged and aggressively marketed and may make irresistible claims, including for cure or recovery.

The majority of approaches and interventions have not been scientifically or independently evaluated. This does not necessarily imply that they are ineffective or bad but it does leave the way open for misleading claims to be made. One should always be skeptical about 'quick fixes' or high cost programmes where there are no independently validated published outcomes.

There are those interventions where changes to the core condition of autism or a 'cure' is claimed. This is a controversial area and one which quite naturally causes offence to many individuals with an autistic condition. There are some specific medical conditions associated with autism and which can be treated (PKU) but in the main the causes of the condition are unknown.

Other approaches claim to improve the disabling effects of autism or to deal with the secondary or associated effects of the condition, to improve communication and behavior or to reduce anxiety. There is rather more research associated with this latter category, but even then, the impartiality of much of this work is often lacking.

There is no shortage of claims and the internet has both opened up the opportunities for our understanding but also our vulnerability. The unregulated nature of the internet has guaranteed the proliferation of intervention approaches, some well meaning, some unscrupulous or hazardous but most untested. Parents and to a degree professionals too are vulnerable to misleading claims or approaches that may be suited to one individual but not another.

The area is in urgent need of high quality scientific research to conduct large scale trials of interventions and how these affect the various individuals with autism making use of them.

For parents thinking about a particular intervention it is important to ask:

A) About the treatment programme

- What is the stated outcome (aim) of the programme?
- What does the programme claim to do?
- How does it work?
- What is the underlying rationale or philosophy?
- How was it developed (e.g. by accident- related to research- clinical experience- personal experience- religious or philosophical belief- alternative explanation extension from another field of medicine or disability etc?)
- Is the philosophy tied to one particular approach?
- Do parents / professionals feel comfortable with stated aims?
- Does it focus on one specific skill or problem or is it a general approach?
- Are treatment goals individual?

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Reference: Mr. Richard Mills (with thanks to Dr. Lorna Wing – The National Autistic Society, Professor Gary Mesibov & Professor Eric Scopler – Division TEACCH), The National Autistic Society, UK.



- Is there written information?
- Is there a brochure?
- How long has the programme been in existence?
- How many individuals have been treated and what was the outcome?
- Is the programme open to suggestions from families and other professionals?
- Exactly what is involved for the child/adult and family (processes and procedures)?
- What is the length of the course of treatment?
 - Maximum
 - Minimum
 - How much parental time is involved?
 - How much professional time is involved?
- Does the programme use techniques that are:
 - Painful or hazardous?
 - Distressing for the child?
 - Socially unacceptable (e.g. sanction based?)
 - Illegal (e.g. physical interventions, confinement or use of illegal substances)

B) Credentials of programme staff

- What is the background of programme director and staff?
- What are the qualifications of the programme director and staff?
- What is the experience of the programme director and staff with individuals with autism?
- Does the programme have experience and expertise working with similar children to my child?
- Is the programme imported under licence or by agreement from elsewhere?
- If so what are the links with the main programme?
- Does this programme replicate the main programme or a modified form of the main programme?

C) Costs

- How much **in total** does the programme cost?
 - Enrolment fee
 - Training
 - Materials
 - Fees
 - Administration charges
 - Travel costs
 - Follow up or recurring costs such as re-registration
 - Other additional costs
 - Can costs be refunded if the programme is not effective?

D) Facilities, equipment and modifications

- Will special adaptations or modification to property be involved?
- Will special equipment be needed?
- Will we have to suspend other treatments?
- Will we have to suspend or modify other family activities?

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- Is there co-ordination between programme and other professionals (e.g. psychologists, teachers, therapists, doctors)?
- Is there any follow-up?

E) Effectiveness of intervention programme

- Is there supporting evidence from
 - Other parents?
 - Research publications?
 - Independent research or evaluation?
- Can I talk to other parents who have been involved with the programme?
- Have there been many cases where the programme has not worked and what were the circumstances?
- Have there been any cases where the programme has made things worse and what were the circumstances?
- Are there any side effects or negative effects of the programme?
- Will there be any negative or stressful implications for family life?
- Is there a complaints process?
- Have there been any complaints about the programme or legal disputes?
- What is the attitude of the programme to independent scrutiny or evaluation; and has this been done?

The Charity Research Autism now has funding for the development of COMPASS, a web based directory of all interventions in autism. This will include:

- What it is (detailed description)
- The rationale behind the intervention
- Costs
- What it claims to do
- The evidence (research and other)
- Details of any scientific studies

It is hoped that this information will be available and that a trusted source of advice, completely independent and impartial is expected to launch in the spring of 2007.

In summary, parents (and professionals) should look beyond the claims at the evidence. It should be borne in mind that many of the interventions in use may be effective with one individual and not another and claims made for one child's improvement may well be genuine but will not necessarily be in the case of your child.

Parents obviously should be wary of programmes where there may be hazardous consequences for their child. They should also be cautious of programmes, which are reluctant to be independently scrutinized or evaluated or which promise 'quick fixes' at high cost. The impact of a programme on the quality of life and well being of other members of the family should also be taken into account and advice sought from knowledgeable professionals and from other parents.

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